Divided We Fall: How Competition Can Compromise the Cause
By Janice P. Dutcher, M.D. and William P. Bro

Recent advancements in the treatment of kidney cancer have brought hope to thousands of patients diagnosed with the disease and their loved ones. But there is still much work to be done, and now more than ever, it is imperative that advocates remain united in their efforts to promote further research to fight this deadly disease. Unfortunately, recent fractions in the kidney cancer advocacy community have challenged this unity and threaten to thwart this encouraging progress.

Patients are the first casualty when advocacy groups begin "competing" to serve a relatively small disease population such as kidney cancer. When someone is diagnosed with a serious disease, one of the first places they turn to for information and support is voluntary health organizations. However, when multiple organizations purport to represent their best interests, or worse, when they appear at odds over their approach to advocacy, it only serves to confuse patients.

Paula Bowen, board chair of the Kidney Cancer Association (KCA), suggests greater cooperation would serve everyone's interests: "Kidney cancer advocacy organizations should consider development of working relationships with other domestic kidney cancer-specific charities. A unified approach is more effective than diverse cancer-specific groups promoting disparate agendas. We all want the same outcome."

Unity is perhaps even more important when it comes to research advocacy. The U.S. Congress provides approximately $27 billion for medical research every year through the National Institutes of Health (NIH), [1] but the kidney cancer lobby is weakened when multiple organizations are contending for the limited attention and resources of legislators.

"The bottom line is that kidney cancer is not a 'famous' disease," says Christopher Wood, MD, an associate professor of urology at the University of Texas M. D. Anderson Medical Center. "It doesn't affect the numbers that breast and prostate cancer do. Anything that is done to dilute or detract from the message that kidney cancer is an important malignancy worthy of research should be avoided."

Some disease advocates have begun lobbying the federal government to earmark funds specifically for kidney cancer. However, this approach is not only contrary to the KCA's position, but is also fundamentally at odds with the Congressional directive for NIH funding, as stated in the Appropriations Committee's report accompanying their recommendations for FY2005:

> The Committee reiterates its longstanding view that NIH should distribute funding on the basis of scientific opportunity. The Committee urges the Director and the Administration to continue to resist pressures to earmark, set aside and otherwise politicize these resources…. For example, there are no directives to fund particular research mechanisms, such as centers or requests for applications, or specific amounts of funding for particular diseases.[2]

And NIH, in turn, concurs with this recommendation:

> From long experience, we know that research aimed at one target often hits another, e.g., a gene causing breast cancer in mice plays a role in the development of brain tissue. It is impossible to attribute research and discoveries like this to one disease.[3]

Regardless of political necessity, the KCA agrees that broad-based medical funding is better for everyone. "We must remember that cancer research is not performed in a vacuum," says Bowen. "Research in one cancer area often leads to discoveries in another." A good example of this principle in action is the drug gemcitabine. First approved by the FDA for treatment of pancreatic cancer, [4] it has since shown promise in reducing the size of renal cell tumors. [5,6]

By forming a unified front and working toward common goals, kidney cancer advocates can effect significant contributions in the fight for a cure that may ultimately benefit the entire cancer patient population.

References

1. NIH Budget page. National Institutes of Health Web site. Available at: http://www.nih.gov/about/budget.htm. Accessed November 17, 2005.

2. Committee Reports page. The Library of Congress THOMAS Web site. Available at: http://thomas.loc.gov/cgi-bin/cpquery/T?&report=hr636&dbname=cp108&. Accessed November 17, 2005.

3. Setting Research Priorities at the National Institutes of Health page. National Institutes of Health Web site. Available at: http://www.nih.gov/about/researchpriorities.htm#funds. Accessed November 17, 2005.

4. GEMZAR FAQs page. GEMZAR Web site. Available at: http://gemzar.com/treatment/faqs.jsp?reqNavId=3.7#history_mbc. Accessed November 17, 2005.

5. Neri B, Doni L Gemelli MT, et al. Phase II trial of weekly intravenous gemcitabine administration with interferon and interleukin-2 immunotherapy for metastatic renal cell cancer. J Urol. 2002;168(3):956-958.

6. Therapies page. Kidney Cancer Association Web site. Available at: http://www.curekidneycancer.org/index.cfm?pageID=40. Accessed November 17, 2005.

©2005 Kidney Cancer Association and respective copyright holders. All rights reserved. Reproduction without written permission is prohibited.